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ABSTRACT

Project LIFT is a 3-year model demonstration program designed to provide family-focused, home-based early intervention services to rural parents of handicapped children under 3 years of age. The LIFT model encompasses: (1) development of an Individual Family Service Plan, (2) case coordination to assist families in identifying and obtaining community resources and to facilitate interagency collaboration and cooperation, (3) home-based interventions focusing on infant development and family adjustment, and (4) a modified transdisciplinary team approach. The Individual Family Service Plan documents both family and child strengths and weaknesses as based on family and child assessments. A case coordinator is assigned to each family and acts not only as the primary interventionist, but also is responsible for contacting other agencies or community services the family may need, accompanying the family on clinic or medical visits, etc. The home-based interventions emphasize teaching the child a cause and effect relationship between their behavior and something happening within the environment. Interaction patterns between parents or other family members and the handicapped child are analyzed by videotaping the family's interactions and evaluating them. (JDD)

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# PROJECT LIFT: A RURAL FAMILY-FOCUSED EARLY INTERVENTION MODEL

Since the legislation of Public Law 94-457, birth to three programs for children with disabilities have become a major focus of concern with early childhood special educators. This becomes more crucial in terms of designing a quality program to meet the needs of families of infants with severe/multiple disabilities or who are severely chronically ill who also live in rural areas.

In a rural area, parents experience frustration in a variety of ways. Transportation difficulties associated with long distances between their own homes and the tertiary medical centers where their specialists reside, combine with exasperation over the lack of respite, nursing care, or even educational services in their own area. In addition, many lack the knowledge or the resources to shift through rural social services, health, and mental health management systems to acquire the assistance they need for their child. They often feel isolated and without formal or informal support systems to help them cope with the challenges they face in raising a child with severe disabilities.

Project LIFT, a three year model demonstration grant, was designed to address the many issues facing families in rural areas. Crucial to this model is a family-focused home-based, early intervention service delivery system.

## Project LIFT Overview

One of the major goals of LIFT is to develop a model that could be replicated in other rural areas across the country. The LIFT model encompasses the following features: a) a family-focused intervention approach including the development of an IFSP (Individual Family Service Plan) which includes both child and family goals; b) case coordination designed to assist families in identifying and obtaining community resources and facilitate interagency collaboration and cooperation; c) home-based interventions focusing on three infant-oriented components: 1) Responsive Play, 2) Making Things Happen, 3) Function Abilities, and four family-oriented components: 1) Family Adjustment and Acceptance, 2) Routines and Family Functions, 3) Social Supports, 4) Knowledge and Use of Community Resources; and d) a modified transdisciplinary team approach to interventions which includes an infant specialist, motor specialist, and communication specialist as team members.



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Project LIFT was specifically designed to meet the needs of infants and toddlers under three years of age who have a documented exceptional need or a biological condition that is known to manifest in substantial functional limitations (at least a 50% delay relative to gestation age) in two or more developmental areas or to manifest a severe chronic illness which interferes with daily functioning for more than three months in a year and causing hospitalization for more than one month in a year.

## Individual Family Service Plan

The central structure for the home visit model is based on the IFSP, or Individual Family Service Plan. This plan documents both family and child strengths and weaknesses as based on family and child assessments administered during initial home contacts. Family assessments include:

1) A survey of Family Strengths and Needs - which measures the family's strengths and allows them to identify their needs in the areas of financial, informational, support, and recreational.

2) A Daily Routine - which maps out a general schedule of daily events within the home setting and the quality of interaction between family members and child during these events.

3) An Eco-map - which provides a visual sketch of the support systems in place for the family and the quality of this support, and lastly

4) A checklist of community resources the family is aware of and may wish to utilize.

The child assessments consist of: 1) The Carolina - a developmental assessment for infants and toddlers, 2) The Brinker-Lewis hierarchy - to assess the child's level of contingency responsiveness, and 3) the SARS - a scale which measures interaction between child and parent, and parent and child.

When these assessments have been completed, the family and the case coordinator jointly determine both family and child goals. These goals then become the basis for intervention within the home.

Although child goals have long been the primary focus of an individual education plan, the addition of family goals, particularly those generated by the family members themselves is fairly unique to the early intervention models of the past fifteen years. LIFT philosophy adheres to the principle that the child, rather than being a lone entity is rather part of a family unit whose behaviors and functions interface one upon the other and

whose mutual interaction is the key to success or failure for the child and the family unit as a whole. Therefore, by focusing on family needs, the interventionist is in turn also addressing the needs of the child. Goals may be very personal such as helping one family member obtain a counselor or a support group, or more global such as assisting the family in developing better support to one another during times of crises. Like child goals, specific criteria are developed to measure success and document progress. Child goals will include those to develop functional abilities in the developmental domains (including specific therapy goals), goals to develop contingency awareness (an understanding of cause and effect behavior), and responsibility to the environment, and goals to enhance child/parent and parent/child interactions. Goals might include developing a mode of communication, promoting engagement in interactive games with a parent or other caregiver, or utilizing an adaptive switch devise to develop contingency responsiveness in the child.

Targeted goals are implemented in weekly home interventions. In addition, as needs change or families request, and at least every three months, goals are reviewed and revised or updated as necessary. Data is collected regularly to document progress and completion of specific goals. In this way, both family and child can benefit from the structured intervention LIFT provides.

## Case Coordination

As was mentioned previously, each family has an assigned case coordinator. Perhaps a better name for this interventionist would be co-case coordinator as one of the primary emphasis of the LIFT model is to teach families to become their own advocates and case coordinators. The case coordinator is assigned to a family based on both the primary needs of the child and those of the family as a whole. As LIFT has a modified transdiciplinary team, if, for example a child's primary needs appear to be in the motor area, the case coordinator would be the occupational therapist.

The case coordinator not only acts as the primary interventionist but also is responsible for contacting other agencies or community services the family may need; arranging for joint staffings with therapists or other professionals who may be working with the child or family to maintain continuity of service delivery systems, and accompanying the family on clinic or medical visits to the tertiary medical centers to provide support, information gathering or sharing with physicians and specialists to assist the family in interpreting medical diagnosis and terminology, and to insure that follow-up takes place once the family returns to their own community. In addition, the case coordinator assists the family in the transition from 0-3 to the 3-5 school program by contacting school personnel, helping the family arrange for school observations

and providing information to the family on possible classroom options for least restrictive environment.

LIFT has developed procedural guidelines for implementing case coordination services to the families of the project which include a format for providing doctors and other professionals with regular progress reports on the child, forms for summarizing agency contacts and specifying assigned tasks and timelines specific to each family for use in interagency staffings, and a transition plan for children who are turning three or who will be moving into a different program. Staff are also being trained to orient families to community systems and agencies as well as to feel more comfortable with medical professionals to elicit self-advocacy for themselves and their child by the time their child turns three. More and more responsibilities are turned over to the parent towards case coordination as time goes on to facilitate this goal.

Staff have found that rural families need the support and coordination of services that LIFT provides, and as families are assisted in this fashion, they become more informed and aware of the services they need for their child and how to get them. In addition, case coordination provides a positive framework for interagency collaboration and consistency of service to the family.

## Developing a Contingency Responsive Environment

Because of the severity of handicapping conditions of children served by project LIFT, and the probability that these children might have very few interactive behaviors within their repertoire, it was necessary to develop a program component that could elicit more responsibility from the child to the environment and vice versa. This would include a system of intervention that would teach the child a cause and effect relationship between their behavior and something happening within the environment. The first step in this system is to show the child that when he/she does something, then in turn, something happens. The second step in this system is to help the child learn that a specific behavior makes a specific thing happen. For example, if a child with random arm movements accidentally hits a switch which operates the tape recorder playing music, the first step is to assist the child in repeating the behavior until he recognizes that something he did actually started the music. The second step is to help the child isolate an arm movement as the behavior which elicited the musical response. As the child becomes aware of this cause and effect relationship between something he does and a response in the environment, he begins to comprehend his own control over the environment which leads him to further exploration and interaction which in turn stimulates future learning and growth.

LIFT staff have found switch toys to be extremely beneficial in teaching contingency awareness to very young children with disabilities. Switches commonly made by LIFT staff include batting devices, various plate switches, and cheek switches. These switches are connected to battery operated toys and equipment such as fans, tape players, and radios, toy animals or vehicles, vibrators or any other objects the child may be interested in.

As the child becomes more sophisticated in his/her imitations, other cause and effect toys and materials can be utilized to take the place of switches. However, for some of the children with severe physical limitations, switches continue to be an excellent learning tool.

## Videotaping to Analyze Interactions

A major area of focus for the LIFT model is the interaction patterns between parent and child and other family members and child. In order to analyze interactions and provide a framework for intervention in these interactive patterns of behavior, LIFT families are videotaped on a regular basis. An assessment tool, the SARS, which looks not only at the child's responsiveness to the parent during interaction but also the parent's responsiveness to the child, is utilized to score videotapes and plan guidelines for possible interventions in this area. Families view the videotapes with interventionists to provide additional feedback on what they feel to be the strengths and weaknesses of the interactions and to help pinpoint areas to work on.

For example, if, while scoring a videotape, the interventionist determines that although the child responds best to tactile stimulation from the parent, the parent seldom touches the infant, she may ask the parent to view the videotape and simply suggest to the parent that he/she notice which cues the child seems to respond best to (or what he/she does that the child appears to like the most). By discussing the tape together after joint viewing, the interventionist can point out that the parent "made the child smile or move about more when he/she touched him/her". Or the parent may notice this and decide that this is something he/she would like to work on.

Another type of approach would be to determine a way to help the parent tune in to a child who gives very few or very subtle cues and use a specific response pattern to increase the child's cueing behavior or expand his own repertoire of responses.

By utilizing videotapes on a regular basis, progress can be noted by parent and interventionist not only in the area of interactions but in other areas of child development as well. Contrary to the idea that families might find videotaping to be intrusive in the

home setting, families enjoy the opportunity to view progress in such a graphic context and have been very willing to participate in this aspect of the project.

## Concluding Remarks

Project LIFT is now in its second year of funding. At this time, as a rural model, LIFT's strengths lie in its individualization of programming to families based on each family and child's unique set of strengths and needs, its attention to family support and accessing community resources for families and its commitment to providing a comprehensive set of services including education, therapies, and case coordination to isolated areas of the state. Family satisfaction and child progress to date would imply that the LIFT model is a viable alternative to quality early intervention for children with disabilities who reside in rural areas. As the model continues to develop and more data is collected, it is hoped that the outcome of this project will provide a model for 0-3 delivery services which could be replicated in other rural areas throughout the United States.